

SECOND REGULAR SESSION
SENATE COMMITTEE SUBSTITUTE FOR
HOUSE COMMITTEE SUBSTITUTE FOR
HOUSE BILL NO. 1407
96TH GENERAL ASSEMBLY

Reported from the Committee on Financial and Governmental Organizations and Election, May 15, 2012, with recommendation that the Senate Committee Substitute do pass.

TERRY L. SPIELER, Secretary.

4905S.05C

AN ACT

To amend chapter 191, RSMo, by adding thereto one new section relating to a sickle cell standing committee.

Be it enacted by the General Assembly of the State of Missouri, as follows:

Section A. Chapter 191, RSMo, is amended by adding thereto one new section, to be known as section 191.117, to read as follows:

191.117. 1. There is hereby established in the department of health and senior services a "Sickle Cell Standing Committee" as a subcommittee of the Missouri genetic disease advisory committee. The committee shall consist of nine members, as follows:

(1) The lieutenant governor or his or her designee, who shall serve as chair of the committee;

(2) The director of the department of health and senior services, or the director's designee;

(3) One member of the house of representatives appointed by the speaker of the house;

(4) One member of the senate appointed by the president pro tem of the senate;

(5) One member who has sickle cell disease or is a family member of persons with sickle cell disease;

(6) One member who is a licensed physician with experience in the diagnosis and treatment of sickle cell disease;

(7) One member with expertise in sickle cell disease research;

(8) One member with expertise in minority health; and

19 **(9) One member from a leading sickle cell disease organization.**
20 **2. The members of the committee, other than the lieutenant**
21 **governor, members from the general assembly, and department**
22 **director, shall be appointed by the governor with the advice and**
23 **consent of the senate. Members shall serve on the committee without**
24 **compensation or reimbursement for expenses incurred.**
25 **3. The committee shall:**
26 **(1) Assess the impact of sickle cell disease on urban communities**
27 **in the state of Missouri;**
28 **(2) Examine the existing services and resources addressing the**
29 **needs of persons with sickle cell disease; and**
30 **(3) Develop recommendations to provide educational services to**
31 **schools on the traits of sickle cell disease and their effects.**
32 **4. The committee shall include an examination of the following**
33 **in its assessment and recommendations required to be completed under**
34 **subsection 3 of this section:**
35 **(1) Trends in state sickle cell disease populations and their**
36 **needs, including but not limited to the state's role in providing**
37 **assistance;**
38 **(2) Existing services and resources;**
39 **(3) Needed state policies or responses, including but not limited**
40 **to directions for the provision of clear and coordinated services and**
41 **supports to persons living with sickle cell disease and strategies to**
42 **address any identified gaps in services; and**
43 **(4) Replacing the genetic testing and counseling program**
44 **eliminated due to lack of funding. The program was an hour-long**
45 **workshop provided to schools on the traits of sickle cell disease and the**
46 **effects of such traits.**
47 **5. The committee shall hold a minimum of one meeting at three**
48 **urban regions in the state of Missouri to seek public input.**
49 **6. The committee shall submit a report of its findings and any**
50 **recommendations to the general assembly and the governor no later**
51 **than December 31, 2012.**
52 **7. After December 31, 2012, the committee shall continue to meet**
53 **at the request of the chair and at a minimum of one time annually for**
54 **the purpose of continuing the study of sickle cell disease in this state,**
55 **the impact of the committee recommendations, and to provide an**

56 **annual supplemental report on the findings to the governor and the**
57 **general assembly.**

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